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CHILDREN'S UNDERSTANDING OF THE
SYMPTOMS OF AIDS

Mary Rebecca Shoemaker

1995

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Children's Understanding of the Symptoms of AIDS

**A Thesis Submitted to the Yale University School of Medicine in Partial
Fulfillment of the Requirements for the Degree of Doctor of Medicine**

by

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CHILDREN'S UNDERSTANDING OF THE SYMPTOMS OF AIDS. Mary R. Shoemaker, Linda L. O'Hare, Donald R. Showalter, Domenic V. Cicchetti, David J. Schonfeld. Department of Pediatrics, Yale University School of Medicine, New Haven, CT.

Symptoms are the outward manifestations that allow children to identify and recognize illness; children's understanding of the symptoms of an illness may be directly related to their understanding of its cause or its means of transmission. This study is the first empiric investigation of children's conceptual understanding and factual knowledge of the symptoms of AIDS. Children (N = 361; grades K-6; 57% black, 24% Hispanic, 19% white; 52% female) attending four public schools in New Haven, CT were interviewed using a semi-structured interview (ASK, AIDS Survey for Kids) that included open-ended questions about the symptoms of AIDS, and for comparison, cancer and colds. Responses were scored for level of conceptual understanding and coded for factual content. For each illness, grade level was the variable most strongly correlated with symptomatology concept score ($R = 0.42-0.48$, $p < 0.0001$), and contributed significantly ($p < 0.0001$) to the variance observed in concept score even after controlling for race, gender, verbal fluency, and socioeconomic status. The mean concept score was lower ($p < 0.01$) for symptomatology of AIDS (2.8 of possible 5) than for cancer (3.1) or colds (3.9). In addition, far more symptoms were named for colds than for either cancer or AIDS. Children who believe that HIV is

spread via each of five potential means of transmission by casual contact were more likely ($p < 0.01$) to cite cold symptoms as symptoms of AIDS. We conclude that there exists a developmental progression in children's understanding of the symptomatology of AIDS. Children have a less sophisticated conceptual understanding and narrower factual knowledge base for AIDS than for colds, and therefore have the capability to increase their understanding and knowledge about AIDS. Furthermore, improving children's understanding of the symptoms of AIDS may diminish misconceptions about transmission of HIV via casual contact.

Acknowledgments

I wish to thank my co-authors for their efforts in helping me accomplish this project, and in particular, I owe my deepest gratitude to Dr. David Schonfeld for his continuous instruction, encouragement, and enthusiasm. I would also like to thank the Pediatric AIDS Foundation for the support of this research through the Samuel Jared Kushnick Student Summer Intern Award. Special thanks go to the New Haven Public Schools - the administrators, teachers, staff, parents, and especially, the students - for their assistance and support of this project.

The results of this research have been submitted as a paper which is currently under review.

Dedication

This thesis is dedicated in memory of Elizabeth Glaser, founder of the Pediatric AIDS Foundation. Before losing her battle against AIDS this past year, Mrs. Glaser courageously spoke out to increase national awareness of AIDS. By educating the American public, her goal was not only to prevent further spread of AIDS, but also to elicit empathy, support, and hope for those already suffering from this disease.

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INTRODUCTION

The need to implement developmentally-appropriate educational programs about acquired immunodeficiency syndrome (AIDS) at the elementary school level, prior to children's initiation of high risk behaviors [1-7], has underscored the importance of delineating the developmental process by which young children acquire a specific understanding of human immunodeficiency virus (HIV) infection and AIDS [7-9]. It is essential to learn not only the facts children know about AIDS, but also the process by which they understand AIDS, that is, how children think about AIDS and what meaning they will give to the various information being taught to them [2,10]. By recognizing what children at different grade levels are capable of understanding, it will allow the educational programs to provide explanations that are more consistent with the children's level of understanding [10].

The developmental sequence by which children acquire concepts about illness in general has been well studied, especially with regard to the concepts of causality and treatment [10-14]. As a developmental process,

the progression is independent of variables such as gender, race, or socio-economic status. Prior studies have shown that with increasing age, children's understanding of both the cause and treatment of illness increases through a series of discrete stages characterized by qualitatively different cognitive processes that reflect the progression from pre-operational to concrete to formal thought processes as described by Piaget [12]. Recent research is just beginning to show that a similar developmental progression characterizes children's understanding of AIDS as well [7,14,15].

With the mandate for developmentally-based AIDS educational programs, it is essential to know more about children's specific understanding of HIV infection and AIDS. Although adolescents' factual knowledge of AIDS has been investigated in several studies [3,7,8,16-19], information about what elementary school-age children know about AIDS is particularly limited [2,4,8,20-22]. More information about how children understand certain aspects of AIDS is needed to create curricula suitable for each age group. Studies performed thus far investigating young children's understanding of AIDS have focused primarily on the aspects of causality, transmission, treatment, and prevention [7,14,23,24].

Learning about children's understanding of the symptoms of AIDS may

further the understanding of how they view the disease as a whole.

Symptoms are the outward manifestations that allow children to recognize illness. With regard to illness in general, children have shown that they understand specified illnesses to have specific symptoms [25]. A collection of symptoms and a label for the illness creates a representation or identity of a particular illness [25]. Crucial to this understanding of symptomatology, however, is to recognize that symptoms of one illness may also be associated with another condition, and that certain illnesses, such as HIV infection, may be asymptomatic.

There are only a few studies, however, that have investigated children's understanding of the symptoms of illnesses in general [13,25-27], and there is only anecdotal mention in the literature about children's knowledge of the symptoms of AIDS [2,4,8]. Children's descriptions of people with AIDS appear in a few reports [4,25], but these descriptions of symptoms have not yet been assessed in the context of a developmental perspective in order to determine what children at different age levels understand about the symptoms of AIDS and how this information can be taught to them.

Research has shown that not only are children aware of AIDS at a very young age [4,22], but that they have many questions regarding the clinical aspects of AIDS [21] and considerable misconceptions about the symptoms of this disease [4].

Studies of young children's understanding of the cause of AIDS has shown that children tend to overgeneralize from a familiar condition, such as the common cold, to attempt to explain the cause of AIDS, for which they have less experience and/or knowledge [14,28]. Since young children have limited knowledge about the symptoms of AIDS, it is likely that they may assume as well that symptoms of a common cold, such as sneezing, may indicate that someone has AIDS. Since children will experience these cold symptoms themselves and see them expressed by family members, such misconceptions can create unnecessary fear and anxiety. Several reports have shown that a large percentage of elementary school-age children have concerns about AIDS [2,20,22,23], including fears of having AIDS when they themselves manifest certain symptoms, such as a rash [2]. On the other hand, not understanding that someone who is HIV-infected may be asymptomatic might lead to the adoption of unsafe behavior at a later age because of an underestimate of true risk.

An appreciation of the developmental process by which children come to understand symptoms of AIDS may provide insight into what children at different developmental stages already understand and are most capable of learning. This has obvious implications for the development of effective AIDS educational curricula for elementary school-aged children.

STATEMENT OF PURPOSE

This project aims to measure healthy, elementary school-aged children's level of conceptual understanding of the symptomatology of AIDS and to compare their understanding of the symptomatology of AIDS to that of other illnesses, namely cancer and colds. We hypothesize that there exists a developmental progression in children's understanding of the symptoms of these illnesses. This project also examines the factual knowledge that children have about the symptoms of AIDS and whether there is an association between children's factual knowledge of the symptoms of AIDS with their concerns about casual contact as a means of transmission of HIV.

METHODS

SAMPLE: The research design and sample have been described by Schonfeld et al. in a separate report [14]. Children enrolled in regular education classes in kindergarten through sixth grade in two public elementary schools and their affiliated middle schools in New Haven, CT were invited to participate in this study. The chosen schools are representative of New Haven Public Schools. Each child was required to

provide verbal assent and written parental consent in order to participate.

Interviews were conducted by one research assistant (L.L.O.) on 361 children, almost evenly distributed among grades kindergarten through six, which represented 44% of eligible students (9% of invited parents refused consent and 48% did not return the consent forms). The sample's racial distribution (57% black, 24% Hispanic, 19% white), socioeconomic status as measured by the students' school lunch status (55% free, 9% reduced-price, 36% full-pay), and gender distribution (52% female, 48% male) were highly representative of the elementary school population of New Haven Public Schools (56% black, 22% Hispanic, 20% white; 55% free, 7% reduced-price, 38% full-pay lunch; 47% female, 53% male).

RESEARCH INSTRUMENTS AND PROCEDURES:

ASK (AIDS Survey for Kids):

The ASK is a standardized, semi-structured interview of approximately 30 to 40 minutes duration, modeled after the interview protocol of Perrin and Gerrity for general physical illness [12,29]. The instrument was developed by David J. Schonfeld, Susan R. Johnson, and Ellen C. Perrin and is detailed in a separate report [14]. The ASK has been shown to measure children's conceptual understanding about AIDS along a developmental continuum that characterizes children's acquisition of critical health concepts and provides

developmental information unavailable through the use of true-false or multiple choice questionnaires [14]. Because many children were unfamiliar with the term "HIV," "AIDS" was used to refer to both HIV infection and AIDS. The questions specific to symptomatology are one part of the ASK interview, which also contains open-ended questions about causality, treatment, prevention, transmission, vulnerability, and irreversibility that are not included in this report. The ASK includes one open-ended question with three optional probes, shown in Table 1, inquiring about both the child's conceptual understanding and factual knowledge of the symptoms of AIDS, and, for comparison, of colds and cancer. The ASK also contains forced-response (yes/no) questions regarding five specific modes of transmission of HIV by casual contact, as listed in Table 2.

For the symptomatology questions, each response was probed in a standardized manner by the interviewer until the child indicated that he or she could provide no further information. One research assistant (L.L.O.) conducted all 361 interviews, each of which was audio-recorded and transcribed verbatim. All interviews were scored blindly from the transcriptions at a later time by the senior author (M.R.S.).

The scoring scale for conceptual understanding of symptoms was developed for this study by the senior author (M.R.S.) and parallels the scales for the

concepts of causality, treatment, and prevention as described in a prior report [14]. To create a scoring scale for symptomatology, a sample of approximately 50 interviews was selected at random and the responses to the questions of symptomatology were reviewed without knowledge of the age, grade level, race, sex, or socioeconomic status of each child. These sample responses were then stratified into categories felt to represent increasing levels of sophistication in children's understanding of the symptoms of illness, yielding a hierarchically organized scale of 1 to 5 (with a higher score indicating a more advanced level of conceptual understanding). Concept scores are based on the conceptual sophistication of the response, independent of its factual accuracy, as outlined in Table 3. For example, the response "you get a toothache" received a score of 4 for conceptual understanding, since the child specified a concrete symptom, even though a toothache is not an accurate symptom of AIDS. For each illness, a child received only one concept score, representing the highest level reached in his or her response. Responses in which a child indicated that a person with the particular illness would be asymptomatic were scored separately. All 361 interviews were scored for one illness at a time to eliminate bias within the scoring of one child's responses across the three illnesses.

In addition to the conceptual level of each response, the content of

responses were recorded and coded by category (Table 5). The content codes were selected by the senior author (M.R.S.) by reviewing approximately 50 transcribed interviews and grouping the symptoms named into discrete categories. All categories mentioned in each response were recorded, thus multiple codes were allowed. Only those responses attaining a concept score of 4 or 5 were coded for content, since the remaining responses lacked specific content for coding.

The responses to the symptomatology questions of all interviews were scored for concept and coded for content, using a detailed scoring manual, by the senior author (M.R.S.) who was blinded to the child's age, grade level, race, gender, socioeconomic status, and Peabody Picture Vocabulary Test-Revised (PPVT-R) score (described below). A random sample of 25 interviews was scored independently by another member of the research team (D.J.S.) to quantify inter-rater reliability. The interviews were scored in two sets (N = 10 and N = 15) over time to measure for rater drift.

Observed agreement was greater than 95% for symptomatology concept scores for all three illnesses, using a linear weighting system for partial agreement [14]; weighted Kappa was greater than 0.80 for all three illnesses, representing excellent inter-rater reliability [30-32]. Similar good (>0.60) to perfect inter-rater reliability was observed for the coding of content items for the three illnesses with 96-100% overall agreement for all

content categories; weighted Kappa ranged from 0.65 to 1.00.

The five forced-response questions regarding specific modes of disease transmission via casual contact were scored as either yes or no by the senior author (M.R.S.).

Other data: Demographic data including age, gender, race, grade, and school lunch status (as a measure of socioeconomic status) were obtained for each child from school records by Schonfeld et al. The Peabody Picture Vocabulary Test-Revised (PPVT-R) [33] was administered to each child (by L.L.O.) prior to the administration of the ASK and served as a measure of verbal fluency and an estimate of cognitive ability.

ANALYSES: The analyses were planned and performed by David J. Schonfeld, Donald Showalter, and Domenic Cicchetti.

We calculated Pearsonian R to examine intercorrelations among the symptomatology concept scores for the three illnesses and, for each illness, the correlation between symptomatology concept score and grade level. Concept scores for symptomatology of each of the three illnesses were dichotomized and analyzed by the Jonckheere test of ordinal trend [34] to

determine whether or not a linear association between grade level and the proportion of children with a more sophisticated level of conceptual understanding exists. Comparisons were then made of the mean symptomatology score among the three illnesses using a repeated measures analysis of variance; pair-wise post-hoc analyses were made with the Dunn Test [35]. For each of the three illnesses, a linear regression model was then constructed with symptomatology concept score as the dependent variable and gender, race, school lunch status, and PPVT-R score as independent variables. Comparisons of the various content themes in children's responses between children responding yes or no on each of the five questions regarding casual contact were analyzed by Chi-square.

RESULTS

Scores for the concept of symptomatology for the three illnesses (AIDS, cancer, and colds) were moderately intercorrelated (Pearsonian R ranged from 0.34 - 0.42, $p < 0.0001$). Grade level was the variable most strongly correlated with the concept score for each of the three illnesses (Pearsonian R ranged from 0.42 - 0.48, $p < 0.0001$). To assess further the nature of the relationship between grade level and concept score, scores for each of the three illnesses were dichotomized into low (1-3) and high (4-5) levels (see

Table 4). For each illness, as grade level increased, there was a consistent developmental progression in the percent of high level conceptual responses ($p < 0.0001$, Jonckheere test of ordinal trend), indicating a highly statistically significant linear trend [34,36].

In the Figure, the mean concept scores for symptomatology of AIDS, cancer, and colds are shown for each grade level, demonstrating, for each illness, a consistent increase in mean concept score with progressing grade level. The mean concept score for all grade levels combined varied significantly among the three illnesses studied ($p < 0.001$; repeated measures analysis of variance). The mean score was lower for the symptomatology of AIDS (2.83) than for cancer (3.12), which in turn was lower than the symptomatology of colds (3.90). All three pair-wise post-hoc comparisons were significant at $p < 0.01$ (Dunn Test).

For each of the three illnesses, a linear regression model was constructed with symptomatology concept score as the dependent variable, and gender, race, school lunch status, and PPVT-R score as independent variables. In each regression model, grade level contributed significantly to the variance in concept score ($p < 0.0001$).

The content of children's responses to the open-ended questions about the

symptoms of the three illnesses were also analyzed. Table 5 lists, by category, the symptoms most commonly named. Since the more immature responses (concept score ≤ 3) could not be coded for content, the content analysis only reflects responses demonstrating the higher levels of conceptual understanding (i.e. concept scores of 4 or 5). In addition, responses for those children who indicated that the illness is asymptomatic ($N = 24$ for AIDS, $N = 15$ for cancer, $N = 0$ for colds) are also not included in the content analysis. There are greater than 361 total content responses (for colds), since multiple content codes were possible for a given child.

Table 6 shows the number of responses with codable content (for responses with concept scores of 4 or 5) for the five questions regarding specific modes of transmission of HIV via casual contact. In addition, it shows the percentage of these responses that contained specific mention of symptoms of an upper respiratory infection (URI), demonstrating that children who answered yes to each of the questions regarding transmission via casual contact were more likely to mention non-specific URI symptoms in their responses than were children who answered no ($p < 0.01$; Chi-square). There were no responses in which a child made specific reference to symptoms suggestive of pneumocystis pneumonia; all responses coded as URI symptoms were compatible with symptoms of a common cold.

DISCUSSION

This study is the first empiric investigation to systematically examine children's conceptual understanding and factual knowledge of the symptoms of AIDS. The results substantiate the hypothesis that symptomatology is a concept with a characteristic developmental progression, as outlined in Table 3. Through the use of the ASK, it was shown that with increasing age, children demonstrate greater sophistication in their conceptual understanding of the symptoms of AIDS. A similar developmental progression is seen for their understanding of the symptoms of cancer and colds. This progression parallels that of children's conceptual understanding of causality, treatment, and prevention as described previously [14].

Children have a higher conceptual level of understanding, regardless of accuracy, of the symptoms of more familiar illnesses such as a cold, than for either cancer or AIDS. This suggests that children have the conceptual capability of understanding the symptoms of AIDS at a higher level of sophistication, at least as high as they do for colds. Furthermore, there were 559 total responses coded for content for colds, in comparison to 203 and 273 for AIDS and cancer, respectively. This difference implies as well

that children have a broader factual base and familiarity with the symptoms of colds than they do with cancer or AIDS.

Due to the protean manifestations of AIDS and to the fact that a person with HIV infection may be asymptomatic, we were unable to score responses for factual accuracy. However, this study begins to delineate the categories of symptoms that children name when describing AIDS, as well as to measure the rates of responses within each of these categories.

Children who believe that AIDS is spread by casual contact (e.g. touching, kissing, or sharing a cup with someone with AIDS) are more likely to name nonspecific symptoms consistent with the common cold as symptoms of AIDS than are those children who do not think AIDS is spread by casual contact. Teaching children accurate symptoms of AIDS may, therefore, help to alleviate their misconceptions and anxieties about transmission via casual contact.

The results of this study have implications for the creation of developmentally-based educational programs for elementary school-age children and suggest that young children are capable of attaining a higher conceptual level of understanding of the symptoms of AIDS than they currently possess. In addition to a greater conceptual understanding,

children can benefit from factual information about the true symptoms of AIDS. As symptoms are the outward manifestations of illness, not only are they important in identifying and recognizing disease, but also in understanding important disease processes such as causality and transmission. As such, developmentally-appropriate information about the symptoms of AIDS should be included in AIDS educational curricula, even at the elementary grades.

Table 1. ASK Symptomatology Question.

How can you tell if someone has AIDS (a cold, cancer)?

PROBES:

How can you tell if a child has AIDS (a cold, cancer)?

How can you tell if you have AIDS (a cold, cancer)?

How does this let you know someone (a child, you) has
AIDS (a cold, cancer)?

Table 2. ASK: Forced-Response Questions Asked to Assess Transmission by Casual Contact.

If someone has AIDS and that person sits next to you, but doesn't touch you, can you get AIDS?

What if they touch you with their hand?

What if they cough on you?

What if you drink from their cup?

What if they kiss you on the cheek?

Table 3. Sample Scoring Criteria for the Conceptual Understanding of Symptomatology.

1 = "I don't know," no response, or off-subject response (eg. "I won't get AIDS," "It snows outside when it's cold").

2 = Circular responses and/or reference to phenomenon or external sources of information. The child uses circular reasoning (eg. "You have AIDS") or refers to a phenomenon associated with the illness, such as a cause, treatment, or consequence, as if it were a sign or symptom of the illness. In addition, a child may cite an external source of information, such as a mother or doctor who told the child he/she had the certain illness.

Examples: "You're sick" (circular)
 "You catch it" (cause)
 "You don't go to school" (consequence)
 "You take medicine" (treatment)
 "My mom told me" (external source of information)

3 = Vague allusions to feeling or looking different or funny. The child acknowledges that the person is feeling or looking different but does not refer to any specific symptom or sign in his/her response.

Examples: "You look funny"
 "You feel sick"
 "You look sad"

4 = Specific and concrete symptoms, signs, and/or diagnostic tests are named. The child names specific symptoms or signs of the illness but makes no comparison of these symptoms or signs to that person's normal state of health.

Examples: "You cough"
 "You have a sore throat"
 "You get a blood test"

5 = Acknowledgment that specific symptoms or signs are characteristic of that illness state or at least more common or extreme when a person is ill. There is a direct comparison of the "sick" state with the "well" state.

Examples: "Your temperature is higher than normal"
"You get watery eyes and your eyes don't
usually water unless you are crying"
"The test shows something wrong with your
blood"

Asymptomatic = The child indicates that the illness is asymptomatic or lacks signs that are apparent to observers. This is distinguished from a score of 1 (eg. "I don't know") in that the child must demonstrate clearly that he/she understands that the symptoms aren't visible (eg. "I don't know because you can't see it"). Also, "asymptomatic" is distinguished from a score of 2, where reference is made to an external source; "They tell you they're sick" is scored as a 2 whereas the response, "They have to tell you, otherwise you can't tell" is scored as "asymptomatic."

Table 4. Dichotomized Concept Scores (Low/High) by Grade Level.

Grade	AIDS			CANCER			COLDS		
	N	N	%	Low * High **	%High		Low * High **	%High	
K	30	10	25.0	33	6	15.4	21	19	47.5
1	40	9	18.4	31	18	36.7	12	38	76.0
2	30	19	38.8	26	25	49.0	2	49	96.1
3	31	24	43.6	17	40	70.2	0	57	100.0
4	21	24	53.3	12	38	76.0	0	51	100.0
5	15	30	66.7	12	34	73.9	0	51	100.0
6	13	40	75.5	11	41	78.8	0	61	100.0
z = 6.88			z = 7.36			z = 8.37			
P < 0.0001			P < 0.0001			P < 0.0001			

* Low: Concept Score of 1-3

** High: Concept Score of 4 or 5

Table 5. Coding of Symptom Content for Each of the Three Illnesses: Number of Children Providing Responses for Each Content Area and Percent of All Children With Codable Responses* in Each Content Area.

Category	AIDS		CANCER		COLDS	
	N	%*	N	%*	N	%*
Medical Test	45	28.8	59	29.2	21	6.4
Weight Related	39	25.0	14	6.9	4	1.2
Activity Related	23	14.7	36	17.8	32	9.8
Skin Related	57	36.5	72	35.6	38	11.7
URI Symptoms	17	10.9	47	23.3	304	93.3
Eye Findings	7	4.5	12	5.9	28	8.6
Gastrointestinal Symptoms	9	5.8	15	7.4	28	8.6
Temperature Related	3	1.9	10	5.0	72	22.1
Headache	2	1.3	1	0.5	32	9.8
Arthritis/Joint Symptoms	0	0.0	1	0.5	0	0.0
Tumor or Mass	1	0.6	5	2.5	0	0.0
Lymphadenopathy/Swollen Glands	0	0.0	1	0.5	0	0.0
	-----		-----		-----	
TOTAL	203		273		559**	

* Percent of children with codable responses, i.e. responses with concept scores of 4 or 5 (N = 156 for AIDS; N = 202 for cancer; N = 326 for colds).

** Totals may be greater than 361 as each symptom category mentioned in each responses received a content code, therefore allowing multiple codes.

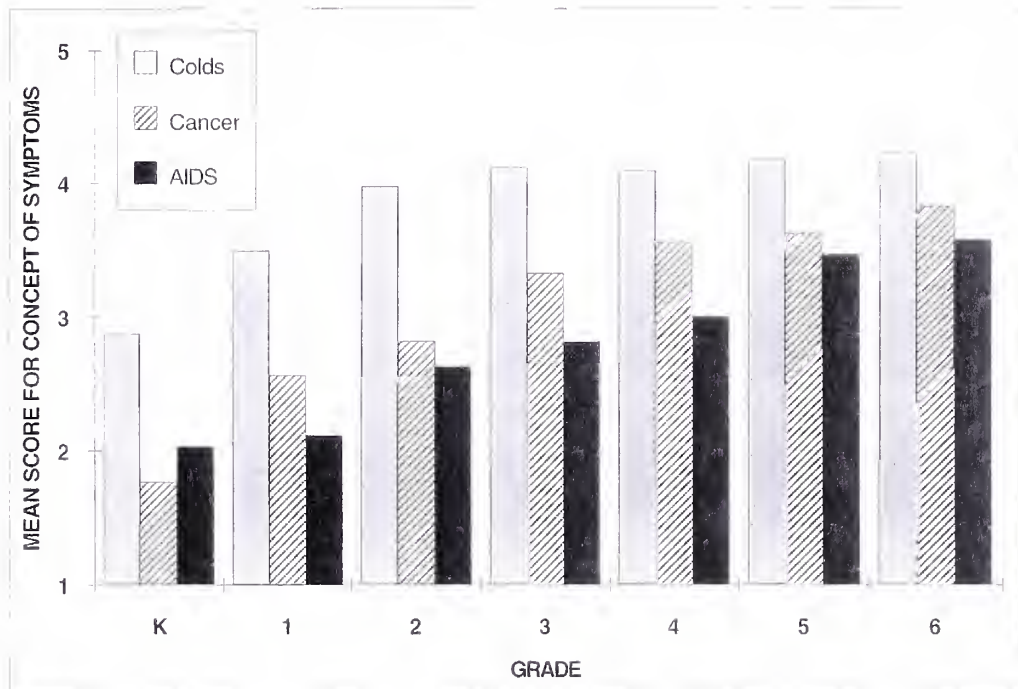
Table 6. URI Symptoms Content Codes as a Function of Responses to the Five Questions Regarding Transmission via Casual Contact.

Casual Contact Method	# Responses *		# (% of responses) Mentioning Nonspecific URI Symptoms **
Sit next to	Yes	19	6 (31.6%)
	No	133	11 (8.3%)
Touch hand	Yes	51	13 (25.5%)
	No	98	4 (4.1%)
Cough on you	Yes	93	17 (18.3%)
	No	54	0 (0.0%)
Share cup	Yes	104	17 (16.3%)
	No	45	0 (0.0%)
Kiss you	Yes	70	13 (18.6%)
	No	72	2 (2.8%)

* Number of responses with codable content, i.e. with concept scores of 4 or 5.

** $P < 0.01$, Chi-square for each comparison between children responding yes vs. no for each question of transmission via casual contact.

Figure: Mean Score for Concept Symptomatology for Each of the Three Illnesses (AIDS, Cancer, and Colds) as a Function of Grade Level.



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